Diabetes in the shadow of daily life: factors that make diabetes a marginal problem

Anders Ågård¹
MD, PhD

Vanía Ranjbar²
PhD

Susann Strang¹,²
RN, PhD

¹The Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden
²Angered Hospital, Angered, Gothenburg, Sweden

Correspondence to:
Susann Strang, Angered Hospital, Box 63, 424 22, Angered, Gothenburg, Sweden; email: susann.strang@gu.se

Received: 21 October 2015
Accepted in revised form: 18 December 2015

Abstract
The primary aim of this qualitative study, which was based on interviews with 24 patients with diabetes mellitus, was to identify factors that influence patients’ willingness and ability to adhere to prescribed medicines, to recommend lifestyle choices and to acquire a deeper understanding of the way these factors influence adherence. The starting point for the study was our belief that it may be of pivotal importance for health professionals to address patients’ life experiences, present life situations and cultural background, as well as their conceptions and attitudes, in order to understand why some patients have or may encounter difficulty in following treatment recommendations and realising treatment goals.

Four main themes related to the primary research questions were identified. Patients with diabetes may regard diabetes as a lifelong follower but not a real problem: a trifle in relation to the daily struggle with difficulties; something out of one’s control; something not worth giving up the good things in life for. In our opinion, the main result of this study is that patients may view diabetes as a marginal problem in relation to other burdens and troubles in life, such as other somatic diseases and symptoms, mental illnesses due to previous traumatic experiences, concerns for loved ones and economy.

We argue that the desired goals in terms of adherence and outcomes for patients with diabetes in general need to be adapted to what is desirable and realistic for the individual patient. Copyright © 2016 John Wiley & Sons.

Practical Diabetes 2016; 33(2): 49–53

Key words
diabetes mellitus; patient compliance; health behaviour; cultural diversity

Introduction
It is an important and challenging task for health care professionals to support their diabetes patients in adhering to medical prescriptions and advice on lifestyle. In fact, adherence is a means of reaching a desirable end, which includes an improvement in clinical parameters, such as HbA1c, lipids, blood pressure and weight, as well as increased psychosocial well-being, empowerment and knowledge among patients. Adherence has been defined in slightly different ways. For instance, when it comes to treatment and advice for living with diabetes, the following meaning has been proposed: the degree of agreement between an individual’s behaviour and the medical prescription. Similarly, medical adherence has been defined as: the extent to which a patient’s medication taking coincides with medical or health advice. Several factors or variables influence the degree to which patients change their behaviour and adhere to prescriptions. They include individual factors, such as insufficient motivation, unwillingness, coping abilities, stress, trait anxiety, depression, drug use, health beliefs and denial of risks. Socio-cultural factors include: social and family support, ethnicity, and the impact of diabetes on significant others. For instance, if family support is lacking, it is more difficult to adhere. Eating the same traditional food as the rest of the family, even though it contains a great deal of fat and calories, may be prioritised ahead of the prescribed diet regimen. Accessibility to and the quality of the health care system, the presence of community disease programmes and the working situation are examples of environmental factors.

The starting point for this study was our belief that it may be of pivotal importance for health professionals to address patients’ life experiences, present life situation and cultural background, as well as their conceptions and attitudes, in order to understand why some patients have or may encounter difficulty in
following treatment recommendations and realising treatment goals. As a result, the prerequisites for health professionals to give advice on diabetes and to set realistic treatment goals, adapted to the individual patient, may be improved. Moreover, one study has shown that this kind of patient-centred consultation can also lead to improved outcomes in terms of reduced HbA1c.7

The primary aim of this qualitative study was to identify factors that influence patients’ willingness and ability to adhere to prescribed medicines and to recommended lifestyle choices, and to acquire a deeper understanding of the way these factors influence adherence. This study is part of a larger interview study of patients with diabetes in a multicultural community in Sweden.

Methods

Patients

The study group consisted of 24 patients with diabetes mellitus. They were recruited from a medical outpatient clinic in western Sweden, in an area with a high incidence of immigrants and a generally low socio-economic status. The prevalence of cardiovascular diseases, type 2 diabetes and smoking is greater here compared with that of the general population.8,9

Patients over 18 years of age, with type 2 diabetes and no history of severe, or obvious, psychiatric disorder, were eligible for the study. Purposive sampling was used in order to include a diversity of patients with respect to gender, age, country of birth, native language, educational background, levels of HbA1c and comorbidities (maximum variation); (Table 1). The recruitment continued until data saturation was reached – that is, when further interviews did not provide any additional qualitative information.10

Data collection

Based on the above criteria, the medical staff identified potential participants for the study.

Contact details for those accepting to participate were forwarded to the researchers who then arranged for a face-to-face interview with the respondent. The interviews took place at the clinic, were conducted by the second and the third author between September 2013 and October 2014, and lasted between 20 and 80 minutes. Seven patients (hereinafter called respondents: ‘R’) were interviewed through an interpreter.

Based on the research question and the open-ended, inductive nature of the study, one main interview question was formulated: ‘Can you describe what living with diabetes means to you?’ Additional questions were asked to further clarify the degree of impact diabetes had on the respondents’ daily life and to address their views and experience in relation to adhering to prescribed treatment regimens and health advice. The interviews were recorded and transcribed verbatim.

Analysis

The methods used for analysing data were manifest and latent content analysis. The manifest part started from the respondents’ actual statements. The aim was merely to describe or summarise what the respondent had said about living with diabetes. The latent or interpretative analysis aimed to identify the complexity of the matter and to acquire a deeper understanding of the underlying meaning of the text. This was based on finding common patterns in the respondents’ stories.11 The analysis was performed in several steps. An example of the analysis is shown in Table 2. The text was first divided into meaning units, i.e. essential statements linked to the research questions, and then condensed and labelled with codes, which were abstracted into eight sub-themes and subsequently four themes (see Table 3). Quotations were used to exemplify the findings.

The interviews were read through several times to obtain a sense of the whole. To improve the inter-rater reliability, some of the transcribed interviews were analysed separately by the authors. Similarities and inconsistencies in the interpretations of the text were discussed and considered when new descriptions were formed (dialogical inter-subjectivity). As a test of internal validity, a physician specialising in diabetology and a diabetes nurse were asked to read and comment on the main findings. They judged them as reasonable from a clinical perspective. During the interviews, a dialogical validation was performed, i.e. similar questions were asked in different contexts to ensure that patients’ views were fully and correctly captured.12,13

Ethics approval of the study was obtained from the Regional Ethical Review Board in Gothenburg, reference number 414-13. All respondents received verbal and written information about the study and signed consent forms prior to participation.

Results

A lifelong follower but not a real problem

No big deal. Every patient had been affected by diabetes in some way and almost everybody talked about life becoming more structured and limited. However, a common pattern was that the respondents did not feel that diabetes was a particularly severe disease. Rather, it was perceived as a minor issue in life, something that only implied certain
practical problems, including the need for an increased focus on food and medicines. Life in general went on as usual. In fact, some said that being diagnosed with diabetes had not changed their lifestyles substantially. Moreover, those who had had diabetes for a long period of time generally had incorporated the management of the disease as a part of or as routine in their everyday life. A few patients even expressed gratitude for being able to live in a country where there is access to insulin and care. Diabetes thus became subordinate.

‘For me, diabetes is only something I have and I will have it as long as I live. I don’t think so much about it. It is like having a cup of coffee in the morning… or going to the laundry,’ (R2).

Symptoms, not blood sugar levels, matter. Another reason for not ascribing diabetes any particular importance was the lack of symptoms associated with high blood glucose levels. As a result, some respondents felt that they did not bother about complications at the moment, even though they knew they could occur in future.

‘The health care unit tested my blood sugar level and once again I had more than 30. However, I had no symptoms of diabetes this time either,’ (R16).

A trifle in relation to the daily struggle with difficulties

Burdening circumstances. Many respondents said that their perception of living with diabetes was dependent to a great extent on burdening circumstances and troubles in life. One example was a middle-aged man who felt unable to manage his diabetes because a work project had failed. This precluded his ability and willingness to take responsibility for his diabetes. Another patient responded directly with worries about the future when asked about living with diabetes.

‘It’s difficult to live with diabetes because every day I get a new problem. I live alone. I can’t get anyone to help me at home. Yes, every time I go to sleep, I pray to God to end my life so that I don’t have to wake up. I don’t see any joy in life,’ (R5).

Psychiatric, social and existential problems reduced the quality of life and down-played the significance of having diabetes. Some respondents had painful memories from wars and escaping from their home

### Table 2. An example of meaning units, codes, sub-themes and theme

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed text</th>
<th>Codes</th>
<th>Sub-themes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent: ‘I would probably have better blood values if I ate less and walked more, of course. But I do nothing myself to make it better. I have no motivation at all. You can’t imagine how much vodka and beer we have in stock at home! And an extra freezer packed…’ Interviewer: ‘Is there anything that would make you change your habits?’ Respondent: ‘No. Only if I could get a spark of life again. It would surely be better if the whole damn society changed, huh, and how easy is that…?’</td>
<td>My blood values would be better, if I ate less and walked more and the damn society changed. But I do nothing to make it better. I am missing the spark of life</td>
<td>Blood values, Lack of motivation, No activity, Bad society, Missing motivation</td>
<td>Burdening circumstances</td>
<td>A trifle in relation to the daily struggle with difficulties</td>
</tr>
<tr>
<td>Respondent: ‘My daily life is not just that, the sugar disease. My blood pressure is up and down. And I have an inflammation in the lumbar vertebrae. It is not just one problem, there are problems with everything. Sometimes life can be hard to live, it is not that comfortable’</td>
<td>My daily life is not just the sugar disease. I have inflammation, high blood pressure. It is not just one problem. Sometimes life can be hard</td>
<td>Not only diabetes, Several diseases, Life is hard</td>
<td>Less important compared with other diseases and symptoms</td>
<td></td>
</tr>
</tbody>
</table>

### Table 3. A summary of the results: four themes and eight sub-themes

#### Factors that make diabetes a marginal problem

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lifelong follower but not a real problem</td>
<td>• No big deal</td>
</tr>
<tr>
<td></td>
<td>• Symptoms, not blood sugar levels, matter</td>
</tr>
<tr>
<td>A trifle in relation to the daily struggle with difficulties</td>
<td>• Burdening circumstances</td>
</tr>
<tr>
<td></td>
<td>• Less important compared with other diseases and symptoms</td>
</tr>
<tr>
<td>Something out of one’s own control</td>
<td>• Diabetes as a predetermined condition</td>
</tr>
<tr>
<td></td>
<td>• No use trying</td>
</tr>
<tr>
<td>Not worth giving up the good things in life for</td>
<td>• Preference for a good life rather than living right</td>
</tr>
<tr>
<td></td>
<td>• Reasons for not exercising</td>
</tr>
</tbody>
</table>

The health care unit tested my blood sugar level and once again I had more than 30. However, I had
countries. Others longed for their homes or worried about their relatives in their home country. Some said that they had lost faith and, as a result, they did not have the strength either to look to the future or to care for their diabetes.

'I wish that life was peaceful, but so many innocent people are murdered – and the children. Yes, it affects my disease. I don’t feel well. As a human being, you can’t help but be affected by what you see and hear,' (R12).

Less important compared with other diseases and symptoms. Apart from diabetes, many respondents had a combination of other diseases. A clear pattern emerged. Medical conditions, such as cardiac diseases, high blood pressure, inflammations, chronic obstructive pulmonary disease and depression overshadowed the importance of having diabetes. Moreover, symptoms (e.g. sleeping problems) and treatment (e.g. for tuberculosis or leukaemia) related to these diseases were perceived as barriers to the control of diabetes.

'Heart failure sets the limit for everything. In my opinion, having diabetes does not have a substantial impact on my capacity. The diabetes is merely something that goes along. It is nothing that really bothers me. I just have to check the values every day and take insulin on demand,' (R10).

Something out of one’s own control. Diabetes as a predetermined condition. Some respondents felt that they had got diabetes because it was predetermined or because they were victims of certain circumstances. Factors that were thought to give rise to diabetes included: stress, fate, a difficult childhood, conflicts, having lived under a death threat, war and homesickness. Diabetes was regarded as something evil that, through no fault of their own, had affected them. As they were not responsible, there was no point in trying to influence the disease and, as a result, no incentive to adhere to lifestyle advice.

'I’ve always had a poor view of myself because I had a miserable childhood. And, of course, it affects everything; well, that’s why I’m ill,' (R9).

One respondent who had been prescribed weight reduction felt that there was no point in trying to change eating habits as all his/her relatives were overweight.

'The only thing the doctor complains about is losing weight. No matter how hard I try, I can’t manage to do it. I have been stuck between 84 and 85 kg. I can’t get down any further. I’m just like my parents. They were at exactly the same level. So, it has to do with the genes. And you can’t change them,' (R3).

No use trying. Respondents conveyed a sense of helplessness and lack of responsibility in coping with diabetes and, thus, a sense of resignation. For instance, a patient who felt that injecting insulin was unpleasant stated that it was unnecessary to destroy one’s body with injections, as it did not matter at all whether or not she took care of her health. Furthermore, one respondent claimed that society should be blamed for his lack of motivation to change his lifestyle. Another patient claimed that, as it was difficult to find a certain kind of food in Sweden, her diabetes could not be treated properly.

'There is a centre that mixes plants and leaves of olive trees and honey. These things treat diabetes because olive leaves are able to regulate sugar... this treats diabetes, hypertension and even high cholesterol. I’ve tried to get hold of it from the other country, but the problem is that I don’t have anyone who can travel with me so I can bring the stuff home,’ (R5).

Not worth giving up the good things in life for. Preference for a good life rather than living right. The majority of the respondents had received advice from a nutritionist and knew what they should eat and drink. In spite of this, some of them reported not being willing to refrain from tasty food and alcohol, at least not to a greater extent. The social and enjoyable dimensions of food were considered more important than eating the right food. In fact, some felt that the diet that was prescribed, apart from not being as tasty as the food they used to eat, could make or had made cooking more complicated and meals more boring.

'The diet and the food that I got at the hospital were like getting some kind of medicine. But, at home, you have a family and you want to hang out and you want to live a little, kids come and so on. You want to have a reasonably good life. So I cross the limits sometimes,’ (R6).

Reasons for not exercising. Similarly, even though the majority of the respondents were quite aware of the positive effects of physical activity, some of them took almost no exercise at all. They said that they were lazy, unwilling to exercise or felt that exercise was boring. It was more convenient to remain on the couch or sit in front of a computer. Additional explanations for not exercising were presented, including: pain, fatigue, depression, sleep problems, lack of experience and financial problems. Moreover, some were worried that physical activity could be potentially harmful to the heart. To summarise, these respondents had decided not to change their diet, exercise more or live a highly regulated life, at least not to a greater extent.

'I try to go out for a walk now and then. We have also been training at the gym. That makes you fit. However, I guess we’re lazy. We spend lot of time in front of the computer,' (R17).

Discussion. The results of this qualitative study highlight a number of factors that could influence diabetes patients’ lives, as well as their adherence to advice and prescriptions, and which might therefore be worth considering in clinical practice. As shown in the study, some patients reported they were not willing to give up enjoying good food and drink together with families and friends, nor force themselves to perform boring and unpleasant physical activities, nor live a highly-structured life. As a result, patients may actively choose the good things in
life at the expense of living the right life in respect of their diabetes. The fact that some patients do not perceive diabetes as an immediate threat, or feel that potential future consequences of diabetes are predetermined or cannot be predicted are other reasons for not changing habits. These results corroborate those from other studies. In our opinion, the main result of this study is that patients may view diabetes as a marginal problem in relation to other burdens and troubles in life, such as other somatic diseases and symptoms, mental illnesses due to previous traumatic experiences, concerns for loved ones and economy.

The degree to which the results of this study can be generalised to populations in different settings can be called into question. The interpretation of data and about researchers’ bias in the research process and the interpretation of data and about reproducibility – i.e. the fact that different researchers may not come to the same conclusions – is also embedded in qualitative approaches. We have attempted to ensure validity by explaining the research process and the interpretation of data in a convincing manner. Our aim has been that health professionals would find the results and key points useful in the practical care of patients with diabetes. The use of interpreters may have implications for the results if what is translated is not precisely that which the respondent has stated (for example, if interpreters instead summarise or in other ways omit information). The alternative, however – i.e. to include only respondents fluent in Swedish – would not have been a viable option for the study purposes.

Health care professionals may feel frustrated, or that they have failed, when their patients with diabetes do not adhere to treatment and lifestyle recommendations or do not experience certain outcomes. In this situation, and before blaming oneself or the patient, it is important to consider the reasons for being unsuccessful and alternative strategies for supporting patients. It may be worth bearing in mind that a substantial extra burden is placed on patients in their daily life by having diabetes and that patients’ willingness and ability to cope with restrictions and recommendations and to live according to tightly prescribed routines vary for several reasons. As a result, desired goals in terms of adherence and outcomes for patients with diabetes in general need to be adapted to what is desirable and realistic for the individual patient. Moreover, according to the ethical principle of autonomy, patients do in fact have a right to make decisions related to their own body or health, including the right to say ‘No’ to treatment proposals and to choose not to follow lifestyle recommendations.

We strongly recommend that health care professionals learn about the way their patients view living with diabetes, or, to put it more simply, better get to know their patients and their preferred type of care in order to enable person-centred care. As patients’ views, wishes, feelings and concerns may shift from time to time, the perspective of the patients needs to be addressed on a regular basis. The Danish philosopher, Søren Kierkegaard, successfully summarised what it is basically all about in just a few words: ‘If I want to succeed in bringing a person towards a specific goal, I must first find where she is and start from there.’

Acknowledgements

We would like to thank Marie Schönander, MD, and Ingela Abrahamsson, RN, for reading and discussing the qualitative analysis of the qualitative study.

The study was supported by a grant from AstraZeneca AB’s research funding.

Declaration of interests

There are no conflicts of interest declared.

References